

# Quality Measures Workgroup: PT Family Engagement

## Draft Transcript

October 13, 2010

### Presentation

#### **Christine Bechtel – National Partnership for Women & Families – VP**

This is Christine Bechtel with the National Partnership for Women and Families, and my illustrious co-chair, David Lansky, is on the phone. Do we have anybody from ONC who needs to make some opening remarks before we dive in? Okay. I'll do the role of Judy Sparrow and say, I know this is a public phone call, so we will make sure there's an opportunity for public comment towards the end of the call.

Let's do some introductions. This is Christine Bechtel. I know we have David Lansky, but we've got Paul Wallace, Gene Nelson, and Jim Weinstein. Do we have anybody else, workgroup members that want to introduce themselves?

All right. Everybody should have received the materials that were sent out earlier today. They included some notes from our last call, as well as a new spreadsheet for us to work on today. If you read through the materials, you may have been surprised to see that you were potentially assigned a subgroup to work on offline, and I think we had a little mis-queue on that, so don't worry. You're not on the hook for having supposed to have done homework, at least yet.

What we'll do today is do a quick review of the sub-domains and the definitions that we discussed on the last call, decide whether we want to keep the domains or if there are any we want to combine or any we want to remove, and then we'll go through the domains, particularly focusing on those that we didn't get to last time, so we did a fair amount around self-management, for example, and some on shared decision-making and patient experience. We will go through those. What we'd like to do today is really focus on what is it that we want to measure, and then we've got two more calls scheduled after today. We've got a call October 13<sup>th</sup> at 2:00 eastern, and we've got a call October 22<sup>nd</sup> at 10:00 a.m. eastern, 10:00 to 1:00. We will use those calls to dive more specifically into measures where they exist, particularly for 2013, and really flushing out measure concepts for 2015.

For those of you who may be joining the workgroup for the first time, the context for this work is to make some recommendations back to the policy committee, particularly around the kinds of measures that would be helpful in measuring meaningful use for stage two and stage three. In November/December, ONC intends to issue a request for information to ask for comments on the kinds of measures that exist that might be ready for 2013 and the measure concepts that need to be developed for 2015. They will subsequently issue a request for proposal for organizations like measure developers and health systems and others to set about the work of actually turning those measure concepts into actual measures or, where we have actual measures, evolving them further if need be.

What we really want to focus on here is the domain of patient and family engagement, recognizing that it's a challenging domain. The quality measurement enterprise, I would suggest, has not focused hugely on this area in particular, so we definitely have our work cut out. Our hope is to really focus on identifying measure concepts, what is it that we want to measure, and then backing into what the specific quality measures might be if they exist and, if not, making sure we give some substantive guidance to ONC in terms of what should go into the RFI and the subsequent RFP about developing those measures based on the concepts that we recommend.

We also have some methodologic issues that we'll need to tackle, as we go through and look at the concepts, and figure out what the particular platforms and methods are for collecting this information, again, in order to inform the RFI. So we will be tackling that as well. David is going to talk about that a little bit later. We'll probably ask for some volunteers for a subgroup to work on some of those issues in the meantime. With that, let me ask David Lansky if you've got anything that you would like to add at this time and whether the agenda sounds okay to you and to everybody.

**David Lansky – Pacific Business Group on Health – President & CEO**

That was a very good job, Christine. Thank you. My only add, which maybe someone from staff can clarify as well, I think we need to start thinking about what we say in the RFI, that is, what are the domains and measure concepts for which we would like the measurement community to provide input on. I think that's really, by the end of this month, that's the principle deliverable. Then the specific measures, and even the measure concepts to some degree, are kind of icing on the cake, and we'll have a little more time in November, I think, and also, of course, after we get input from the measurement community to come back to that issue. We can really nail down maybe some measure concepts within, that will be a big, helpful .... I'd appreciate any clarification about whether they have a better sense now of what they think the RFI would need to specify.

**Christine Bechtel – National Partnership for Women & Families – VP**

Allen, are you on the phone, Allen from ONC? I know Josh could not join us today, so Allen Trailer was going to, but we may have to come back to that question if he's not yet on the call. Does that agenda for today sound good? I'll open it up for questions as well.

What we'll do is do a quick review of the domains from the last call and the definitions that we discussed, and decide if we need to roll any up or eliminate any, and then begin the work of looking at the measure concepts that need to be developed. Then it may be more appropriate for us to then do, as actually the notes from the last call say, and ask some of the measurement experts to do some offline work, looking at refining the measure concepts and measures where they exist. Questions, thoughts, or additions to that agenda?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

In terms of the measure domain, do we need to differentiate 2013 versus 2015, or is this point just one or the other?

**Christine Bechtel – National Partnership for Women & Families – VP**

We haven't differentiated the domains themselves, but we do need to differentiate the measures or the measure concepts in 2013 and 2015. One of the ways that, as you know, Gene, from being on the last call that we addressed that was thinking about having some of the, for example, measure of decision quality under the shared decision-making domain that there may be some specific measures of decision quality that are ready, and that we would want to ask for input on that in the RFI. But that for 2015, it may be more focused on a broader measure construct around are decisions really in line with patient preferences and things like that. The measure versus the measure concept may be different for 2013 versus 2015, particularly for areas where the measures aren't especially robust. Does that help answer your question?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

That's great. Thank you.

**Christine Bechtel – National Partnership for Women & Families – VP**

Other questions or thoughts?

**Paul Wallace – Kaiser Permanente – Medical Director**

Actually just using the shared decision-making example, I think we may also run into scenarios where there are an abundance of trial measures that no coalescence around a common measure, so there are 50 different ways that people have measured concordance between preference and service delivery, but nobody has done it the same way more than once. Those may also fall into the 2015 bucket, I would guess.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes. That's a great example, Paul, because my suggestion would be that in that situation, we would say that we might solicit some comments. We might advise ONC that they could solicit comments in 2013 for whether there are measures that decision quality or shared decision-making that are ready enough for prime time to implement in 2013. But if not, then they need to use the RFI to really flush out how that state needs to evolve to find those common measures for 2015. Does that sound right?

**Paul Wallace – Kaiser Permanente – Medical Director**

Yes.

**Christine Bechtel – National Partnership for Women & Families – VP**

Other thoughts or questions? Why don't we go ahead and dive in? I'm looking at the spreadsheet that was sent around earlier today. We've got the first domain of self-management, which is sort of ... defined as activation and consumer empowerment. Let me run through the domains, and then we'll go through the definition.

The second is shared decision-making, which is bridging the gap between expert and public knowledge, patient communication, safety knowledge. That's the title of that domain. The next domain is patient experience of care. The next domain is patient level outcomes. The next is health status. The next is patient preference. The next is family caregiver engagement followed by health activities coordination.

Now I think this list has somehow—we've grown it a fair amount since our last call, so it's the first thing that we want to do is figure out how we might be able to combine or if there are any areas that we want to take off the table. Let me go through the definitions, and we can edit the definitions as we go so that we make sure that we understand them, and then come back to the question of which of these might be combined or eliminated or added ... if that makes sense to folks. Okay.

The first, self-management, the definition that we discussed last time was the patient understands what their role is in their own care process and has the knowledge, skills, and confidence to move forward in this role. These would be measures of health behaviors and patient competency in self-management. Any comments on that?

**M**

Is this for specific conditions? Self-management, is that for what we would call preference based decisions? Is that for chronic disease conditions? Are you not wanting to define that?

**Christine Bechtel – National Partnership for Women & Families – VP**

I think what we had talked about was sort of the general concept of self-management as being applicable to lots of different conditions, chronic or acute. But the notion of how you insure that the consumer understands their role and is equipped to engage in self-management behavior serves the self-efficacy side of, I believe I can manage my diabetes well. But then self-management, we probably should add to this definition also being the tools and resources to in fact do the self-management.

**M**

Yes.

**Dana Safran – Tufts University – Director of the Health Institute**

Sorry to join late. I had some problems getting on the call. Just to understand in terms of what kind of lumping we might be able to do down the column here, oftentimes both self-management and shared decision-making are addressed as part of patient experience of care. I think they're important domains here, but can you just help me, as I'm trying to engage with this group for the first time, in the thinking about how these got pulled out as sub-domains that are separate from a patient's care experience.

**Christine Bechtel – National Partnership for Women & Families – VP**

I would say that we used, in part, and David Lansky can correct me if I'm wrong. Part of this came from the review that ONC contracted with NQF to do. They produced a report called the Gretzky Group Report, which was the report designed to look at sort of the future of quality measurement. Where is the puck going, hence the name. So they had, I believe, originally categorized measures according to self-management, shared decision-making, patient experience, and patient level outcomes. On our last call, we added some domains around health status, patient preferences, and patient/family engagement that we can think about how they might be combined or included.

To answer your question, at least on our last call, the discussion of patient experience of care is often focused on retrospectively what happened. The notion of surveys, whether it's CAPS or some other instrument to ask to the consumer, did your provider engage you in shared decision-making? It's certainly part of patient experience. Did they help you understand how to best manage your condition? It's certainly a measure of self-management, but we also talked on the last call about the need for more patient activation measures on the front end to understand are consumers getting the tools and resources that they need for their own ability to do that self-management rather than just asking a question, did the provider help you understand your condition? We can decide to change that, but I think that was a fair reflection of our conversation. If anybody would like to add anything, that would be welcome.

**David Lansky – Pacific Business Group on Health – President & CEO**

Christine, I think Dana is on a good track though that we did have a couple comments last time that the patient experience bucket with all the sub-tags has become nebulous, and maybe we should break out and clarify that the, in effect, sub-domains that are now lumped under patient experience and the way the worksheet is labeled. Rather than assume that there is one ... called patient experience, we should decide whether the sub-domains that we want to capture, and maybe some of them that Dana was suggesting could be captured through the same data collection methodology of platform or instrument, but we should be sharp about which domains we think are really HIT sensitive and relevant for our overall agenda. This role could go away, the patient experience role, and be replaced by some sub-domains that we think are domains.

**Dana Safran – Tufts University – Director of the Health Institute**

That's really helpful, David. That clarifies it for me that really what we're talking about are the areas of measurement. Not all that's in patient experience of care is something that's relevant to measuring patient and family engagement. So we're looking for what are the domains that relate to patient and family engagement. For sure, the first two that we've got there, self-management and shared decision-making, fit that. I think there are a couple others that are currently, at least in my world, thought of as things that we measure using patient care experience surveys that we'd want to pull out and say that they're important pieces of patient and family engagement like communication quality, and then maybe do away with sort of that all encompassing domain of patient experience of care.

**Christine Bechtel – National Partnership for Women & Families – VP**

In other words, we could then take the CAPS family of instruments. Tenet Healthcare has H-CAPS surveys, whatever. We could take CAPS and survey instruments and integrate that into, because they ask questions around self-management and shared decision-making and certainly patient and family caregiver engagement. Is that what you're suggesting, Dana?

**Dana Safran – Tufts University – Director of the Health Institute**

Yes.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes, I think that makes sense. Do folks agree? I'm sorry to be typing near the phone, but I'm going to go ahead and drop this in.

**Dana Safran – Tufts University – Director of the Health Institute**

Are we making the assumption about these domains as being things that the source of data is going to need to be the patient and/or family members themselves, or are we assuming that that will typically be the case, but it doesn't have to be, or are we trying to find measure where we can avoid using the patient and family members as the source and somehow capture these concepts in some other way?

**Christine Bechtel – National Partnership for Women & Families – VP**

David. It's a methodologic question. Do you want to address that?

**David Lansky – Pacific Business Group on Health – President & CEO**

I think the strong assumption is that we want to capture information directly from patients, at least perhaps family or caregivers, and that raises the ... question given the nature of this particular initiative focused on EHR adoption. While there's a lot of emphasis on having clinicians push summary results and so on to the patient and to, over time, increase the use of the technology for patient engagement, we obviously can't presume that all of ... meaningful users patient ... is connected. So we've agreed to form a little methodology sidebar group to talk about all the implications of that structural problem and whether, so one extreme, for example, we leverage existing patient experience surveys of an entire sample of a clinician's practice and then drill down on the issues around HIT sensitivity, or the ... example, patients who had some e-mail address or some HIT connectivity or have used some HIT service, etc. In either case, what's the methodology implications of taking that approach.

We haven't done any work on that yet. That's a brand new question for us, so we did agree. Christine and I agreed this morning that we would launch a little taskforce in the next few weeks ... I guess that's a long way of saying our desire is to collect information from the patient. We realize that's not a trivial ....

**Paul Wallace – Kaiser Permanente – Medical Director**

The one, I guess, thing I would add is clearly the thing that differentiates this category is the ability to get information from the patient, but a lot of the measures will need to have some aspect of delivery system activity in order to have appropriate context. I'm particularly thinking of like shared decision-making. Shared decision-making for what. If we want to ... we're going to have to know what actually happened.

**Christine Bechtel – National Partnership for Women & Families – VP**

That makes sense, Paul. I'm just not sure what you're suggesting.

**Paul Wallace – Kaiser Permanente – Medical Director**

We just need to have sort of running in the back as sort of what are the – and also to the point that these need to be relevant to HIT. It's just to not lose track of where some aspect of either the measure concept or the measure specification has to get to something other than information we get from the patients.

**Christine Bechtel – National Partnership for Women & Families – VP**

Got it. We've combined patients experience, and I've put CAPS, families, instruments, and other patient experience as surveys into self-management and into shared decision-making because they are one measure of those. Do patient experience surveys have a role in any of the other sub-domains: patient level outcomes, health status, patient preference. Certainly they do in family and caregiver engagement or health activities coordination. We can come back to that as we go through these.

The definition for self-management now reads self-management and patient activation. The patient understands what their role is in their own care process and has the knowledge, skills, and confidence to move forward in this role, and we'll also include resources for self-management. Does that make sense for folks? I'm going to take that as a yes. What we can do is we'll send this around, and folks can make comments as well.

Shared decision-making, the definition that we had talked about previously was, what it says in the spreadsheet is often overlap ... making sure that the patient has the knowledge, understanding, and confidence in making informed decisions. It also includes the quality of decision-making, connecting patients to resources, patient preferences, and assessing if the care that was delivered is in line with the patient's preferences. Now I might suggest a small revision to that, which is to say, making sure, and I think we don't need the reference to the overlap. Making sure that the patient has the knowledge, add resources, delete understanding because I think that is concordant with knowledge. Make sure that the patient has the knowledge, resources, and confidence to make informed decisions. Also includes quality of decision-making, etc. Other changes to this or any disagreement with that? All right, so we don't have to worry about patient experience.

Patient level outcomes, we talked last time about three kinds of outcomes or three states: one being disease and disability, the second being health risk, and the third state being functioning health. Gene, this was a definition that I think you had suggested, if memory serves. So this is a sub-domain that would focus on optimizing these three states and also address patient preferences, activation, feedback communication loop to measure health outcomes. Thoughts on that? It seems to touch the other areas as well, if we like that definition.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

I think it's a bit of a similar conversation about lumping and splitting and being clear about what we mean. If we more or less accepted the WHL idea about measuring health status, health states, and the ... definition, which ... actually three dimensions—disease, risk, and functioning--to measures health states. Then the health states can be measured at the level of an individual person, an individual patient or at a population level. I think we can probably consider, in some way, combining patient level outcome with health status.

The outcomes are continuing transitions from one state to another state at a point in time. First you started at level X or level Y for functioning. It transitions over time. We're starting to go from stage one, stage two, which gets to outcomes at a point in time.

**Christine Bechtel – National Partnership for Women & Families – VP**

Great. Since we do have health risk and disease, disability, and functioning health status, we can go ahead and delete health status. Is that correct? I move the measures from that line up to the patient level outcomes measures. Yes?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

I think that's right. It depends on what we wish to label things. Do we want to make an emphasis on outcomes, on state or status, or some way signal both?

**Christine Bechtel – National Partnership for Women & Families – VP**

State meaning sort of a static point in time currently? What is the distinction?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Yes. I think that that's right. Health status is a point in time. Health outcomes indicates we're going to from a more longitudinal view from time one to a later point in time two.

**Dana Safran – Tufts University – Director of the Health Institute**

One suggestion or possibility on this is because, I think, we want to be sure that this is a reflection of health or functioning at the subcategory of health that maybe the labeling does bring health into it. Maybe this is patient level outcomes because perhaps all the things we're talking about are patient level outcomes. But maybe it's patient health outcomes.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes, I like that because what I've done is edit the definition to reference, as Gene suggested, both at the level of individual patient and the population level, so that makes sense. We'll rename it patient health outcomes. It will be defined as having three states: disease, disability, health risk, and functioning health. So this domain would focus on optimizing these three states at the level of the individual patient or at the population level, and then we've got the ... question of, are we talking about both outcomes or state. Gene, what's occurring to me is if we focus on outcomes, it requires that you measure the current state, doesn't it, in order to improve on it?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Yes. Except perhaps for mortality being an ultimate outcome.

**Christine Bechtel – National Partnership for Women & Families – VP**

Right.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

... alive or dead ....

**Christine Bechtel – National Partnership for Women & Families – VP**

Terrific. Yes. Right. It makes sense. All right, so the next domain is patient preference, understanding and honoring the patient's plan of treatment or care. Is this something that is distinct from the others, or should it be integrated? Is it part of patient shared decision-making, for example? The definition of shared decision-making, and it may be that we need to rename shared decision-making, is that it also includes the quality of decision-making, connecting patients to resources, patient preferences, assessing patient preferences, and whether the care that was delivered was delivered in line with those preferences.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

I think, combining that in does make sense. I don't know if Jim Weinstein is still on the call, but one of the aims of shared decision-making is to put the individual with the choice to make in a position to make the

best decision, consistent with what's known about biomedical efficacy, as well as with the values and preferences. I think one of the aims of shared decision-making is to understand and honor a person's preferences and values.

**Christine Bechtel – National Partnership for Women & Families – VP**

If we integrate patient preferences into shared decision-making, is the category of shared decision-making to narrow? Does it need to say shared decision-making and patient preferences, or should shared decision-making become honoring patient preferences? What do you guys think?

**Dana Safran – Tufts University – Director of the Health Institute**

That's a good way to move forward, I think, honoring patient preferences.

**Paul Wallace – Kaiser Permanente – Medical Director**

I generally agree that they certainly— If you draw the Venn diagram, they very closely overlap. I'm just wondering if we want to retain a sensitivity to things like how people prefer to receive information, stuff on more of a process type level, which will be, to the patient, an index of the quality and responsiveness of the health system, but it's a little different than the main emphasis of shared decision-making, particularly around preference sensitive care.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes. It's in an interesting point. I like parsimony, but on the other hand, you're right because there are a fair number of measures in meaningful use or a fair number of functional requirements that rely on per patient preference. It's resources, after visit summary, discharge instructions, copy of the medical record, and access to information. Off the top of my head, those five functional requirements all say delivered per patient preference, whether it's paper, USB stick, portal, PHR. Is that what you're getting at, Paul?

**Paul Wallace – Kaiser Permanente – Medical Director**

Yes. If anybody wants it somewhere else, but I think we don't want to lose track of those because they show up so prominently in the other areas. If we title the whole category patient preferences and shared decision-making, those are really, in a sense, sort of subsets of – we're then thinking sort of structure or process outcomes. They're going to sort of be structure and process type measures.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes.

**Paul Wallace – Kaiser Permanente – Medical Director**

I think we could want them. We just don't want to lose track of those sorts of sub-concepts that it isn't all about preference sensitive care.

**Christine Bechtel – National Partnership for Women & Families – VP**

Got it. Okay. Good. I've noted both and that we would suggest that ONC get some feedback on the measure of how people prefer to receive information within the new category, which is re-titled honoring patient preference and shared decision-making. Maybe it's just honoring patient preferences and decision-making where share is implicit. That takes us to our last two domains. We have family caregiver engagement and health activities coordination. Family and caregiver engagement, we had talked about engaging and educating the patient's family/caregiver. I sort of am of two minds on this. I think there are two ways we can look at it.

One is that the measures for self-management and patient preferences and patient health outcomes should have a family caregiver domain because, in many cases, you've got older adults or young children



who aren't capable of doing self-management on their own, but the caregiver does it with them for them. It could be integrated in that way, and you could look at a caregiver, a CAPS for caregiver or a functional status assessment for caregivers, for example.

Then the other is a set of measures. The other way to look at it might be a set of measures around how is the family or caregiver, how well are they engaged in healthcare? That might be something that could be assessed through CAPs or other patient experience. The more I'm kind of talking to myself here, the more I'm thinking that family and caregiver engagement should be integrated as a potential measure construct into some of the other domains, but what do others think?

**Dana Safran – Tufts University – Director of the Health Institute**

I would say it strikes me that because it's not always going to be a relevant part of care, and maybe others disagree with that statement, but I'll just ... it won't always be a relevant dimension of care. Therefore, to me, it makes sense to have it there as a domain. The questions would sort of be asked when they're relevant to the condition or to the patient state.

**Christine Bechtel – National Partnership for Women & Families – VP**

Dana, what would the questions be? That's where I'm stuck, because I think the questions would be around self-management, honoring patient or family preferences. I'm not sure. I hear what you're saying though.

**Dana Safran – Tufts University – Director of the Health Institute**

Maybe what that means is that I guess if the family member is going to be answering questions, I agree with you that they're probably answering questions about the same set of domains that you might ask the patient him or herself, but you'd have to ask them differently.

**Christine Bechtel – National Partnership for Women & Families – VP**

Right.

**Paul Wallace – Kaiser Permanente – Medical Director**

To me, it's kind of a rows and columns problem where it's sort of like every one of these measures ought to have some sort of subset of things, which says if the patient could do it, was the family involved or whatever, or was the family involved even when the patient was too, as opposed to keeping it as a separate line? I think it's probably just picking one or the other. There might be some value in just sort of hanging onto it as a separate line for now just so that we don't lose track of this going through the other measures.

**Christine Bechtel – National Partnership for Women & Families – VP**

What I'll do is I'll edit the definition to say, engaging and educating the patient's family/caregiver in each of the above sub-domains. We'll hold it as a row, and I'll put it in as a column, and we'll figure it out later. Allen, you get that job. I know, Allen, from ONC, has joined us.

**Allen Traylor – HHS/ONC**

Yes, I have. Thank you.

**Christine Bechtel – National Partnership for Women & Families – VP**

By the way, has anybody else joined us, because I know that folks had to wait for the operators quite a while? Obviously we heard Dana. Okay.

Health activity coordination is the last domain that we came up with on the last call. This is the notion of connecting the patient to community resources. What do folks think about, should this be a separate domain, and does it have the right name? Is that the right definition?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

This particular area looks as though it's going to be covered perhaps in another tiger team care coordination.

**Christine Bechtel – National Partnership for Women & Families – VP**

That's a good point.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

So we might let that be with that group.

**Christine Bechtel – National Partnership for Women & Families – VP**

What do folks think of that? We'll make sure that the care coordination group is looking at it.

**Allen Traylor – HHS/ONC**

We've been sort of directed to ask that if you can, to continue as if nobody else was dealing with it. Then that way we can roll up recommendations into the larger group, but I think, as for now, we're supposed to act as if it falls under our domain unless otherwise directed. We can take it after this call to the rest of the groups and find out. But that's kind of the direction we've been given so far.

**Christine Bechtel – National Partnership for Women & Families – VP**

How about, in the interest of parsimony, that if I can make an ... ONC will get back to us where we need to go about addressing this domain.

**M**

That would be analogous to the usual state that it's up to the patient to coordinate their care? I'm just kidding.

**Christine Bechtel – National Partnership for Women & Families – VP**

Thank, God. I was about to launch a new diatribe. Good call. All right. Here's where we're at. We've got the first domain of self-management. We've got the second domain, which we've combined a number of things into honoring patient preferences and shared decision-making. We've integrated patient experience into those domains. We have our third domain of patient health outcomes, and then a potential fourth domain of family caregiver engagement and maybe health activities coordination if the care coordination group is not picking that up. I can imagine that they will also say, the patient family group should deal with that, so we'll figure that out. Is everybody okay with those domains and the definitions, as we've agreed to them? Okay. Great.

I'll remind you guys to put your phones on mute because we've got some background noise from somebody on a cell phone. Thank you.

All right. That's great. We've now rolled up and combined our domains and agreed on some definitions. We'll send this around so that folks can, in a quiet moment, take one last look at it. Now we need to turn to making sure we have a sense of what the measure concepts are that we want to address in each of these areas. We've got in the spreadsheet examples of measures that the Gretzky Group and other folks have identified. On the last call, we spent a fair amount of time talking about some potential measure

recommendations, which I have in front of me, but I'm going to double-check. I don't think are reflected on this spreadsheet. Yes, they're not quite yet.

Let me tell you what they were in the first area of self-management. We spent a fair amount of time talking about patient activation. I think we probably don't need to spend a lot more time talking about that, but we do need to make sure the other side of self-management is covered.

What we talked about before was something like percent of patients with an activation score recorded. It could be a measure concept that we would ask for public comments on for 2013. Then in 2015, looking at the percent of patients that have a change, hopefully a positive one, in activation. Does that concept of patient activation cover this domain? I'm not sure that it does. I think there's also a self-management side of this whether you've got the resources that you need to do self-management. What do folks think, or does that cover it?

Why don't we—? I know we don't have Judy Hibbard. I know Paul Tang was interested in this domain, so this may be one where we asked for some offline work, but let me just pause for one second to ask if there are any other comments, and then we'll jump in to shared decision-making.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Dana, do you have comments about self-management and how to measure self-management?

**Dana Safran – Tufts University – Director of the Health Institute**

We do. I think we've got a pretty good approach that's been incorporated into a survey used in California that David is probably familiar with. I think there's a good module on that that is very CAPS-like, intentionally so, and that's fielded annually in California in the statewide survey work that PBGH oversees. There's actually a journal article that describes the validation and the metrics of that set of items.

**Christine Bechtel – National Partnership for Women & Families – VP**

Great. I've cataloged that, and that's something we can ask for input on in the RFI. Any other measures of self-management or measure concepts? In other words, we may not have good measures of self-management, so as we go through our discussion today for each domain, I think if we have some measures, that's great, but we definitely want to also be sure we're focusing on, well, what is it that we want to measure, even where measures don't exist, so that we can help ONC shape their thinking around what measures to fund the development of, if that makes sense. Are there other concepts in self-management that we need to measure, aside from patient activation and the self-management, as the California survey does?

**Paul Wallace – Kaiser Permanente – Medical Director**

I think it's more towards the future, but there's some question to why, once you activate a patient, what do they do? There's the outcome. There's sort of that question of whether activation is an outcome or an intermediate outcome. I think it's sort of an intermediate outcome that's situation dependent. I wouldn't really know how to begin working through that, but I think that it's sort of with the end in mind of improving overall health outcomes. It's important that self-management be directed at things that are actually most productive for self-managing.

**Christine Bechtel – National Partnership for Women & Families – VP**

That's a really good point, Paul. Is that something that we might be able to draw a direct link to the patient health outcomes domain in that we would say, beyond patient activation measures, one of the

ultimate ways that you measure self-management is through patient outcomes. Is that what you're getting at?

**Paul Wallace – Kaiser Permanente – Medical Director**

Yes. I guess it's sort of the dilemma that we've done the splitting piece into these domains, but there are some things from sort of a clinician or health system level that have to roll up across the domains. It's kind of like the sort of medical question is, are we actually pointing patients in the right direction. Now that may be out of scope for this, but I think it's worth keeping in mind that we're going to have millions of activated people running around. We also need to give them some direction for the outlet for their activation.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes, for sure. Great. Other comments on this domain that's self-management?

**Dana Safran – Tufts University – Director of the Health Institute**

I guess the other comment that I would make is that most of the content I know has tried to address self-management around chronic conditions. I wonder whether we can make some progress in a self-management set of items that deal with health risk behaviors and just preventive care in general ... lifestyle issues.

**Paul Wallace – Kaiser Permanente – Medical Director**

The one I think of, while it's not directly self-management, it's sort of like, does mom bring her young kid into the ER. I think those are a self-management type of category, but they wouldn't necessarily get picked up in some of the things that we measure now.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes. For sure. Actually, I know that some of the other domains are looking at overuse of ER, which that's the thing. A lot of these, you can't perform well on without doing lots of other things in patient and family engagement that we would want to measure. Other comments before we jump to the next row?

All right, so the next row is shared decision-making. There were some measures that were suggested. One is an NQF measure around ESRD plan of care for inadequate ... dialysis. The other was a set of decision quality measures that I think come from ... if I'm not mistaken. In our last call, we definitely focused on measures of decision quality, but also recognize that we probably didn't have the right experts to advise on specific measures. Let me ask you guys what you think about the measure concepts, what is it that we want to measure in shared decision-making, and whether there are measures that would accomplish that that we want to make sure are in the RFI.

**Paul Wallace – Kaiser Permanente – Medical Director**

I tend to think of this as sort of three levels. The first is sort of, did it occur. The second is, was it done well? Then there is a third level that says, did it really make any difference? The third one being, a patient could actually reach great comfort with a decision that has nothing to do with the care they actually received.

I think the "did it occur" level is sort of like the NQF measure. Is there something that documents that it actually occurred, and it sort of bleeds over? I think the CAPS measure almost struggles or straddles. A CAPS-like measure almost straddles did it occur and was it done well from the patient's perspective. But the decision quality measures, particularly when they begin to get to concordance between preference and the service actually delivered are really sort of outcomes of shared decision-making, and those are

the complex measures about whether it really made any difference. Did the decision actually impact the care that was given, and did we achieve concordance between preference and service delivery?

I think that the first levels of did it occur probably could be accommodated through either tracking some trackable event or asking the patient in a CAPS-like measure. Was it done well begins to get at whether the patient actually understood what they were making a decision about and whether it made any difference to the concordance piece, I think.

**Christine Bechtel – National Partnership for Women & Families – VP**

Those are great concepts. What I've got is there are three levels. David, is that you trying to say something?

**David Lansky – Pacific Business Group on Health – President & CEO**

Yes. I was going to react to Paul's comment because I generally agree with it. It raises, for me, this question, I think I raised at the last call, that is just a question in my mind about—I guess it's a practical question, as well as a definitional one. Our charge is to ... do clinical quality measures. That's our broad umbrella under which we're operating, so in that respect, I think it's a higher order question ... Paul segregated out. But from a practical point of view, given the newness of some of these domains as broadly used measures, I wondered whether there was a meta-measure or kind of a functional measure, which is whether, in this case, the clinician, the meaningful user is aware of the patient preferences and somehow could demonstrate that they were evaluated and addressed in the treat care plan or the decision-making process.

I raised the same issue in the context of patient outcomes whether there's a meta-measure, which is a kind of closing the loop measure. Did the clinician know the post-treatment patient outcome? Does the clinician have any mechanism in place for ascertaining how the patient is doing six months after a knee replacement or a stint delivered rather than actually collecting the outcome data itself.

Obviously on ... itself, but a more generic, generalizable implementation rather than trying to say, did you collect the Harris ... score? Did you collect the Seattle ... questionnaire? What score did you get on it? Is to have the question, which is whether the clinician captured that type of data for some category of patients. I'm wondering, Paul, if the same approach could be architected for this domain about patient preferences ... addressed. I realize it may take us away from a clinical quality measure towards really a functional measure, so I'm a little ambivalent about it, but I just want to ....

**Paul Wallace – Kaiser Permanente – Medical Director**

I think it's an important aspect of this. One level you could think about would be is there the capacity to share a decision aid and track the results, which you sort of de facto assume that that means that the clinician would have awareness of the patient's preference. That would be something that one could imagine doing. It's not a whole lot more challenging than some of the things that I think are in meaningful use now and it actually comes kind of close to the NQF measure that's there about the ability to actually document that there was an agreement reached of plan of care. It's sort of half a step beyond that if I understood kind of where you were going.

**M**

... when you said that it reminded me of the thinking I was doing earlier about advanced directives as another kind of proxy for patient engagement. At least you can say you had the conversation and it resulted in a ... made available, so you don't know about the quality of the conversation or the decisions that were reached, but it's a proxy of some kind.

**M**

Yes. I guess in my mind it's really going to be a reach. It might be a 2017 measure to try and really get a concordance between whether the patient's wishes were fully taken into concern and that impacted the care delivered, but I think that there are a range of these intermediate things, which will really set the infrastructure so that one could then create an accountability for that other stuff down the road.

**M**

Yes.

**David Lansky – Pacific Business Group on Health – President & CEO**

Gene and Dana, what do you think about this issue of these meta-measures versus direct quality measures?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

This is Gene. I'm still pondering it.

**David Lansky – Pacific Business Group on Health – President & CEO**

Being thoughtful does not fit into the ONC process, Gene. I'm not sure we can –

**Dana Safran – Tufts University – Director of the Health Institute**

I'd say ditto for me.

**Christine Bechtel – National Partnership for Women & Families – VP**

Okay. Well, we'll send this out for folks to react to. I think I've captured, David, your sort of adaptation of Paul's original so we can work on it when you guys see it is probably easier. So what I've got is the three levels: Did shared decision making occur, including was the clinician aware of patient preferences? So there's a measure ... and documenting that it occurred and what the patient's preferences are.

The second level being was shared decision making done well? ... could be helpful here. In other words, did the patient understand what they were making a decision about and all of the implications.

Then third is did it make a difference, which gets to both, the patient's level of comfort with their decision, as well as whether there's concordance between patient preferences and service delivery. Does that about get it?

**David Lansky – Pacific Business Group on Health – President & CEO**

Very good summary.

**Christine Bechtel – National Partnership for Women & Families – VP**

Great.

**M**

Yes.

**Christine Bechtel – National Partnership for Women & Families – VP**

Okay.

**Dana Safran – Tufts University – Director of the Health Institute**

Can I just do a quick process check? I'm sorry. I know this is on my calendar for 2:00 to 5:00. I have to jump off for a phone call here and there in that time slot, so I just want to make sure; is it really 2:00 to 5:00? If so, I'll keep the call live and I'll just use another line to make this other call and come back.

**Christine Bechtel – National Partnership for Women & Families – VP**

I think it depends on how fast we work, so it's possible that we'll end early. I'm sure people would not be heartbroken. I think it just depends. My guess is that we're ready to go; we're going to have two more at least, yes, one or two more domains, so it may not go until 5:00. David?

**David Lansky – Pacific Business Group on Health – President & CEO**

... I'm going to aim to see if we can get off at 4:00, so if we can an hour that would be great.

**Dana Safran – Tufts University – Director of the Health Institute**

Okay. I apologize I have to jump off for a bit. I'll come back as soon as I can, but I'll keep the call live here so I don't have to log back in.

**Christine Bechtel – National Partnership for Women & Families – VP**

All right. Thank you, Dana.

**Dana Safran – Tufts University – Director of the Health Institute**

Thank you.

**Paul Wallace – Kaiser Permanente – Medical Director**

Christine, this is Paul, just process wise; I've got to leave at 3:30.

**Christine Bechtel – National Partnership for Women & Families – VP**

Oh. All right.

**Paul Wallace – Kaiser Permanente – Medical Director**

I'm sorry.

**Christine Bechtel – National Partnership for Women & Families – VP**

Okay. No. That's okay. So we'll definitely try to end at 4:00 so that folks can – uh-oh, Dana's put us on hold.

**Allen Traylor – HHS/ONC**

You know, she can always call back in. Can we go ahead and just drop her line?

**Operator**

I sure will. Just one minute, please.

**Allen Traylor – HHS/ONC**

Thank you.

**Christine Bechtel – National Partnership for Women & Families – VP**

Great. Okay. Allen, if you have her e-mail address you might send her a note saying, "We cut you off."

**Allen Traylor – HHS/ONC**

I will do that.

**Christine Bechtel – National Partnership for Women & Families – VP**

Thank you very much. Okay. So, honoring patient preferences and shared decision making; before we leave the domain, thinking about the concept that we've agreed to, the definition that we also discussed and sort of the label here. Just to make sure we've got all of the concepts, we're talking about bridging the gap between expert and public knowledge, patient communication, safety, knowledge, making sure that the patient has the knowledge, resources and confidence in making informed decisions ... quality decision making, connecting patients to resources and assessing patient's preferences, as well as whether or not care was delivered in accordance with preferences.

Have we covered the major sort of concepts here?

**M**

Well, from the earlier discussion when we lumped the prior category of patient preference into this one there were some other aspects of preference, but I think those actually fit well with David's concept of sort of the meta-measure of was there a place for the physician to be aware of patient preferences, whether they're about aspects of the care they receive or more around the sort of process types of things about how they receive care. Do they want e-mail? Do they want to be called? Do they want their parents to see their records?

**Christine Bechtel – National Partnership for Women & Families – VP**

Got it. Okay. Yes. I actually had that; I just had it in the wrong column. So I've got sort of how people prefer to receive information, although ... to ask you guys, because I think it's hard. There's the how, which is do you want it on paper, do you want it through e-mail; but there is also more broadly probably not just receipt of information, but to communicate, right?

**M**

Yes.

**Christine Bechtel – National Partnership for Women & Families – VP**

Okay. Then we should probably ask what are the other preference sensitive areas we need to ask about. Okay. All right. Any more thoughts on that?

Specific measures that we might think about including in the R-5 would be the measures of decision quality that were identified by the ... Group as well as the ... family of instruments. But then, clearly, what we would say is that there are constructs or measures that need to be developed in accordance with the constructs that we've outlined, the three levels that we've just been talking about. Does that make sense? I'm going to take that as a yes.

Okay. The next domain is patient health outcome. Again, we've defined that as sort of three things; disability, health risk and functioning health. Those are pretty good constructs, I think and we ought to ask for suggestions around what kinds of instruments and measures exist in each of those three areas.

What we have identified for us by the ... Report is an NQF measure around COPD bronchodilator therapy, the Young Adult Healthcare Survey, blood pressure control and functional status. Those are things that we talked about on the last call, but I'm not sure that those really cover well all of the three states, so for example, health risk assessment isn't in here. I'm not sure if ... play on that, but what are the other kinds of either measures or measure concepts that need to be developed in accordance with the three states of disease/disability, health risk and functioning health?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**



This is Gene. A bit on functional health status: The Health of Seniors Survey that CMS uses for Medicare Advantage does have the VR-12 instrument embedded in it at the first module. The Health of Seniors Survey also has; It's a patient reported survey; it also has some indicators of disease status that are self reported. As an example of potential measures, the Health of Seniors Survey and some of the modules, including, specifically the VR-12 would be a good thing to consider –

**Christine Bechtel – National Partnership for Women & Families – VP**

Gene, is that DR, as in Delta, or V, as in Victor?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Victor. V, Victor.

**Christine Bechtel – National Partnership for Women & Families – VP**

Got it.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Good. There is a VR-12 and a VR-36 and those are public domain versions of the SS-12 and SS-36.

**Christine Bechtel – National Partnership for Women & Families – VP**

Got it.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Then, when you start to think about speaking of the issue of functioning for adults the PROMIS work that has been funded by NIH, National Institute of Health, is really terrific and is probably where the future will be going with respect to, let's say, 2015. It's called the PROMIS Calibrated Item Data Bank and there is a very elegant breakdown of the domains of function and the sub-domains of function within PROMIS. The domains of function within, for example, the VR-12 and VR-36 can be cross walked to the PROMIS domain. There it's a way of looking at what the sub-domains of function are. In general, it's physical, mental, social or role function is one characterization of them, but it's quite elegant in the PROMIS taxonomy.

One issue would be functional status for adults. We could probably measure quite well right now and even better in 2015. For children we would need another conversation and another set of recommendations about what might be set for use in 2013 and 2015.

In terms of thinking about a disease status, that domain, or disease outcome, some of the disease outcomes are best gotten from patient reports and some of them are best gotten from what's a diagnostic test or something like a diagnostic test. Sometimes you have a choice of a disease status measure. It could be self-report or a diagnostic test. For example, there's a five-item asthma control measure that is extremely well validated, rather widely used. It's highly correlated with lung function tests, so there you might have a choice of lung function tests or self report. Depression is self report, primarily PHT-9 is not a good diagnostic test for depression. For diabetes hemoglobin A1c is quite good. So when we look at that particular area of disease state it becomes tuned to the disease or the disability and sometimes the best source of information is a diagnostic test or something like that and sometimes the best source of information is the patient report.

**Christine Bechtel – National Partnership for Women & Families – VP**

So here's where I'm struggling: I feel like there are a lot of potential measures in that universe, maybe less so on the patient reported side, but definitely on the diagnostic side, you know, HbA1c or lipid or whatever –

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Right.

**Christine Bechtel – National Partnership for Women & Families – VP**

So the diagnostic test I feel like probably either should come off the table because it's going to be covered in some of the other areas, but I think what's challenging; and ONC has heard me say this before, unfortunately for them; is we don't have a set of clear health goals so that we could say what we're trying to do is reduce the impact of diabetes, focus on improving asthma care and eliminate smoking and reduce obesity. We could focus patient self reports or diagnostic tests in those areas to get at disease outcome. That's going to be our challenge, I think.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Yes. There's another committee again, another Tiger Team, on population and public health, population health and public health, and they're going to, in some ways, probably be going into the same territory that we're in here.

**Christine Bechtel – National Partnership for Women & Families – VP**

Certainly on the diagnostic test side, but I'm not sure on the patient self report side though, Gene. What do you think?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

I suspect you're right, but there is that overlap. Then, just slipping in, I think disease is the most challenging one to think clearly about because it's so potentially highly differentiated. Functional status we can get quite well at a general level.

Going to risk status, there this status primarily, being able to measure that through a report of health behaviors, such as eating pattern, exercise pattern, smoking pattern, alcohol use pattern, seatbelt use pattern behaviors, as well as by a metric for clinical variables, such as those called out by the Framingham Index. So you can probably have a very good general measure of avoidable risk of death that would be a function of ... individual in a population based on both, biometric variables, as well as behavioral/lifestyle variables and it would be extremely useful for adults at the individual or population level. Chris Murray at the University of Washington is developing a measure with his team that will be ready for field testing in January. In a sense it's an updated Framingham approach, but it adds in behavioral factors and the best available epidemiologic data worldwide.

So I think you could probably have a very good general measure of risk status for adults, functional status for adults and then the disease gets, as I said, highly differentiated.

**Christine Bechtel – National Partnership for Women & Families – VP**

Right. Okay. Here's what I have and then I'd like for folks to react: I think where you started, Gene, was functioning health. Is that where the VR-12, VR-3 is? What category is that or is that –

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Yes, a measure of functional health status. It's very widely used.

**Christine Bechtel – National Partnership for Women & Families – VP**

Okay. For functional health status we have some potential measures coming from the Health of Seniors Survey, which includes the VR-12 or looking at the VR-36. There's also a PROMIS Survey from NIH,

which is for adults, and we would need some input on what kinds of functional health status measures might exist for kids.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Right.

**Christine Bechtel – National Partnership for Women & Families – VP**

The second is the risk status area and there are two kinds or two sources of information. One is a patient reported health behavior and the other are the clinical variables that you talked about in the Framingham Index. So what we would do is ask for there to be developed a general measure of avoidable risk of death that is based on both, biometric variables and lifestyle variables at the individual level and the population level and we know that the University of Washington is doing a field test of just such a measure in January.

That covers the two areas and let's come back to the third, but is that correct so far, Gene?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Yes. The University of Washington is currently doing some field testing. They'll have an instrument ready for broader field testing in January.

**Christine Bechtel – National Partnership for Women & Families – VP**

Okay. So that leaves the third area of outcomes. There are two kinds. There are patient self reported and there are diagnostic tests. This is the difference between the patient bringing in their glucose readings and doing a long-range hemoglobin A1c test, right?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Yes.

**Christine Bechtel – National Partnership for Women & Families – VP**

So how do we want to approach? I guess there are two questions. One is, first, do folks agree with the two areas that we just listed, functional health status and risk status? The second question is how do we want to approach health outcome, particularly with respect to diagnostic tests, which I think are going to be covered in some other areas? David or Paul or other folks on the phone, what do you guys think?

I think the area that we need the most help is patient self reports on outcomes and whether there are some potential instruments for self reported outcomes information that we would want to look at.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

David, did you want to say something?

**David Lansky – Pacific Business Group on Health – President & CEO**

I'm sorry ... jump in. I wanted to hear what you had to say, Gene, but my quick thought was, back to Gene's earlier comment, there are plenty of good instruments around and this goes to sort of the architecture of the measurement system, which is a little bit out of our control, but if CMS retains this by specialty menu item approach then it would be a relatively simple matter ... for us to say we think virtually every specialty menu set should include the opportunity for the user to report patient outcomes and then have our RFIRC process solicit from the field; maybe we could come up with a list of 10 or 15 specialties for which we think this is germane; based on the list already in the final rule of stage one, although I don't like the idea of doing it by specialty, but we'll leave that aside at the moment and come up with a list of 10 or 15 or 20 specialties or services or procedures of diagnoses for which we think there are appropriate

outcome tools out there and say basically here is the menu and then say to the development measurement community what have you got in each of these 15 categories. With that ... of the RFI so that then we'd have a menu of qualifying instruments or measures from which the users could pick when their time comes to report in stage two.

**Christine Bechtel – National Partnership for Women & Families – VP**

I like that. I think what we would say is focus on patient reported outcomes and how HIT can enable that for top impact conditions with appropriate outcome tools and we'll ask people to tell us what the top conditions and tools might be.

All right. Good. Other thoughts? Gene, anything more?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Yes. I think as you think about longitudinal care and in the background the NQF ... longitudinal framework for measurement we're in good shape for adults with the functional and risk states. Where you start to get into more complexity is the specific diseases and conditions, but then I think, as David was suggesting, if we were to select some ... conditions that are high volume, high impact, high cost areas, such as asthma in children or depression in adults or total joint replacement or acute myocardial infarction, you could then start to see how all three of the categories of patient outcomes fit and it could be specified for the AMI patient for disease outcomes. This is the best measure for asthma. These are the best measures for depression, etc. So as you start to take on specific clinical sub-populations over time you could make some very good recommendations about disease outcomes, as well as the functional risk.

**Christine Bechtel – National Partnership for Women & Families – VP**

I think that's terrific.

**Paul Wallace – Kaiser Permanente – Medical Director**

This is Paul. I like the approach for a variety of reasons. I think that everybody ... particularly what I think is important is that I think that this approach would actually create an opportunity to better engage specialists. One of the exposures for meaningful use is the ability to broadly engage a bunch of groups and so I like the idea of being able to put this out so that it could raise a conversation with a specialist, like how does your outcome relate to the patient. So I think that would be a helpful framing.

**Christine Bechtel – National Partnership for Women & Families – VP**

Okay. Great. Great. Okay. Anything else on this topic of patient health outcomes before we jump into the last two areas? Okay.

The last two areas are family caregiver engagement and health activities coordination. Now, Allen was kind enough to do some real-time digging and figure out that the care coordination group is not doing anything related to connecting the patient to community resources. They're doing something on medical home and that could include that, but we don't know. So they're focusing on effective care plans, thank goodness, having a medical home and palliative care, so they could have some themes in both, palliative care and medical home, and frankly, care plans too, but we don't know. So, do we know of any measures, but we can probably back up and start with what is it that we're trying to measure in this domain. I think what we started with last week was this notion that we need to measure whether or not patients are getting connected to the community resources and support that they need. I think we need to finish that sentence. Is that to facilitate their self management, for example, in which case it might be something that we build into the self management domain or is it separate? What do folks think?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

This is Gene. There are at least two really clear needs for community connections and one is for health promotion and another is for complex, chronic disease management and care. We could consider connecting with patient's community ... both for prevention and health promotion, as well as for social and other needs beyond medical needs for complex, chronic cases.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes. Okay. Yes. So the concept we would want to measure connecting to community resources for health promotion, complex chronic disease management and care and social or other non-medical needs and support. Does that sound right?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

Right.

**Christine Bechtel – National Partnership for Women & Families – VP**

Okay. That's a good measure concept. I have no clue whether there are any good potential measures in this area. Gene, do you know?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

I do not.

**Christine Bechtel – National Partnership for Women & Families – VP**

I don't either.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

One of the initial motivations of medical home was this; it was for complex, chronic children, because you need so much more than medical resources to manage their care, but I don't know of good measures. There may be. I don't know.

**Christine Bechtel – National Partnership for Women & Families – VP**

Okay. So it's a good construct and I think we can suggest that we get some feedback on it until we figure out if there are ways to measure that. Does that sound right to folks? David, does that sound right to you?

**David Lansky – Pacific Business Group on Health – President & CEO**

Yes.

**Allen Traylor – HHS/ONC**

I can take that to the Care Coordination Team as well, Christine, and see if they'll look at it and see if they have measures that will cover the areas that we need covered.

**Christine Bechtel – National Partnership for Women & Families – VP**

Great. Perfect. Allen, thank you.

So that leaves us with the family caregiver engagement domain. I think this came up in the sort of construct that I originally described, which was this notion that you need to both, have measures in the domains that we've just discussed in cases where the family caregiver is really the sort of primary interactivity point when you've got, for example, an older person who has cognitive disability or things like that. But then there's also this notion that when you have a family caregiver, regardless of whether there is cognitive disability in their family member, you've got to pay attention to their functional status and their health status as well, because we all know that caregivers often ignore their own health at the peril of

everybody else. My guess is that we're probably talking more about the former than the latter, but I think it would be good to articulate the concept here of family and caregiver engagement.

So the first I'll call caregiver as a proxy for the patient in each of the sub-domains. Does that sound right?

Then the second is whether we want to suggest that in treatment instances where there is a caregiver present that we might have a measure related to either their engagement or their health status. What do folks think of that? Okay.

**Paul Wallace – Kaiser Permanente – Medical Director**

This is Paul. I mean I like the idea. I think any boomer has an aging parent and I guess ... I think it's something that could get missed and left out. I think it's important to carry forward. It will be interesting to see how it survives.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes. So, Allen, maybe you and I can work together and I'll send you the notes that I have, but I think what we ought to do on this area is build it into some references to a caregiver in some of the other sub-domains so that we can make sure we potentially have some measures that are relevant for caregivers, but we should ask or we should recommend that ONC ask in the RFI what the right measures for caregivers are.

David, yes? You'd like to say something?

**David Lansky – Pacific Business Group on Health – President & CEO**

Yes. Well, I'm just thinking, going back to the HIT enabled/sensitive construct; this is always a great opportunity for progressive providers to be sharing information with caregivers and engaging them ... I'm just wondering maybe there's a domain here that goes into our patient experience survey or whatever you call it. I don't know how to operationalize that, but I do think we should keep an eye out, at least half an eye on the potential of the technology to really drive improvements in caregiver participation and reduce caregiver burden as we think about it, as we offer up to the community what the measurement construct is we want input on. I think part of it is are you getting out of sort of the campus clinic mentality in the way you engage the caregivers.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes. I agree. Actually, David, your comment brings up for me the idea that we've talked pretty broadly about quality measures for patient and family engagement, but I think that it might be important for us, either on the next call or off-line, to go back through what we've identified, clean it up and really make sure we're thinking about how HIT plays a role in each of these.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

This is Gene. A comment stimulated by David's remarks: In looking at, for example, *The Innovator's Prescription* by Clay Christensen and Jerry Grossman and others, one of the big links to the future that the facilitated tier networks and a lot of the facilitation being enabled by HIT so that, let's say, people ... for a person with Alzheimer's are connected with expert resources electronically for better decision making, as well as social support with other people like them. You can imagine that a large part of the future of complex chronic healthcare will be in the home and it will be done well in the home. It involves the family members and HIT.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes. David, you're not on mute, by the way. On-line communities. Yes. I think that's right. I think that's right and I've added in the reference. That's good.

Okay. So we've come through articulating certainly the concepts that we want to measure in each of the sub-domains. We've collapsed and organized some of the sub-domains. We've got a couple of measures that we know we want to get some input on and we suspect there are probably more out there that we're missing.

What I think we ought to do is work with Allen and ONC to come up with a summary that's a little more digestible to send out to the broader group for review. We can ask at that time that folks take a couple of days and think about additional measures in their fields of expertise that they might be able to suggest for 2013 and then also ask that they review the measurement concept and provide any revisions that they'd like in advance of our next call, which is October 13<sup>th</sup>.

David, I want to ask you in a second to talk about the Methodologic SWAT Team and either appoint yourself some members or ask for volunteers, but in the meantime, does that path of asking folks to review and revise concepts and add particular measures that you know of that we may have missed, particularly for those folks who weren't on the call, does that process make sense for you guys?

Today is October 13<sup>th</sup>, isn't it? So our next call is October 22<sup>nd</sup>. My bad. Oh, boy.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

That sounds good to me.

**Christine Bechtel – National Partnership for Women & Families – VP**

Thank you, Gene. David, does that sound good to you? Also, do you want to talk for a minute about the Methodologic SWAT Team stuff?

**David Lansky – Pacific Business Group on Health – President & CEO**

I'm sorry. I was distracted. I am now back. I'm happy to talk about the Methodology SWAT Team.

I think it surfaced already in this call in a couple of places where there are some challenging issues around how do we ... in a way that meets the generalized quality measures, especially IT enabled generalized quality measures. So I sketched earlier some of the high level thoughts. What I was thinking of doing this week is trying to write down maybe two pages, something really –

**Christine Bechtel – National Partnership for Women & Families – VP**

Oh, David, we lost you. Come back to us, David. All right. So we're losing David. When he comes back he can interrupt, but he's going to essentially ask for volunteers for a SWAT team. What I'd like to suggest is that we probably do that over e-mail as well when we send out the notes and decisions from today so that folks broader than the folks who are remaining on this call can also be part of that work or have an opportunity to be part of that work.

I want to go ahead and open up for public comment in a second, but are there any other thoughts or ideas that folks want to suggest before we go to public comment?

David, are you back?

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

This is Gene. In terms of methods, there may be two huge, broad categories. One might be sort of a ... like approach or Health of Seniors approach where certain patients are sampled with a certain instrument in a certain way at certain intervals. Health of Seniors has a protocol for baseline and follow-up.

Another approach that we've done a lot of work with ... some other places is to embed the patient reported data into the flow of care before, during and after visits so that you have a new information environment that keeps feeding forward the voice of the patient with measures in measured ways so that as the patient moves through the system you can see they're evolving health outcome and their evolving sense of preferences and treatment benefits.

So I think there are probably at least two major models for proceeding to incorporate patient reported outcomes and patient reported information.

**Christine Bechtel – National Partnership for Women & Families – VP**

That's really helpful, Gene. I like that. I hope that David heard that, but if not, I've taken careful notes, because I think that's really good and you may have just gotten yourself roped into the SWAT Team, but I really appreciate that.

**Gene Nelson – Dartmouth – Prof., Community & Family Medicine & TDI**

I volunteered already.

**Christine Bechtel – National Partnership for Women & Families – VP**

Oh, good. Okay. I missed that. Excellent. All right. With that, let's go ahead and open it up for public comment. Bridget, do you handle that?

**Bridget**

Actually, Christine, I was notified by the operator that no one from the public logged in today.

**Christine Bechtel – National Partnership for Women & Families – VP**

Yes. There are like five meetings going on at the same time. How do you pick?

**Bridget**

Exactly.

**Christine Bechtel – National Partnership for Women & Families – VP**

All right. Okay. Good. Well, thank you again. Our next call is October 22<sup>nd</sup> from 10:00 to 1:00, so we'll work with Allen to facilitate some off-line communication and then we'll talk to you again October 22<sup>nd</sup>. Thank you, everybody.

**Allen Traylor – HHS/ONC**

Sounds good.

**Christine Bechtel – National Partnership for Women & Families – VP**

Thank you.

**Participants**

Thank you. Good-bye.